

A novel multidisciplinary educational programme for patients with chronic skin diseases: Ghent pilot project and first results

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Received: 14 July 2010/Revised: 27 August 2010/Accepted: 30 August 2010/Published online: 15 September 2010
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Abstract Chronic inflammatory skin disorders have a major impact on the patients' health related quality of life. Preliminary studies to date have suggested that additional educational and psychological training programmes may be effective in the management of chronic skin diseases, although more rigid methodology is needed. Our purpose was to investigate the effect on quality of life of a novel multidisciplinary educational programme for patients, 18 years or older, with chronic skin diseases. The 12-week intervention encompasses cognitive education on skin and general health issues, and stress-reducing techniques. Quality of life questionnaires were used to assess the participants at baseline and at the end of the program. These comprehend Dermatology Life Quality Index (DLQI), Skindex-29, Psoriasis Disability Index (PDI) and Quality of Life Index for Atopic Dermatitis (QoLIAD). Fifty-five patients participated in six programmes since 2006. Forty-three patients completed the programme. Overall, compared to baseline, DLQI ($n = 39$) improved by 5.64 points ($p < 0.001$; $SD \pm 6.09$), Skindex-29 ($n = 27$) by 19.67

points ($p < 0.001$; $SD \pm 17.37$), PDI ($n = 9$) improved by 7.44 points ($p = 0.019$; $SD \pm 7.60$) and QoLIAD ($n = 13$) improved by 4.39 points ($p = 0.036$; $SD \pm 6.69$) by the end of the intervention. Preliminary results show that the quality of life of the patients with chronic skin diseases improved significantly after participation to the programme. These positive initial results are stimulating to set up a prospective controlled randomised trial investigating the impact on quality of life, the clinical efficacy and the cost-effectiveness of this educational intervention programme.

Keywords Education · Skin diseases

Introduction

Patients with chronic inflammatory skin disorders like psoriasis, atopic dermatitis, chronic urticaria, etc. are prone to psychological distress [11]. The chronic relapsing character of these diseases and the need for continuous, sometimes unsatisfactory treatment causes frustration and disappointment in patients, which in turn might negatively influence the disease course. In periods of stress, exacerbations are often triggered or worsened. The importance of the brain–skin interaction in the etiology of these diseases has therefore received much attention the last years [2, 3, 7]. Increasing the knowledge of the patient about their skin disease and treatment can stimulate participation in the treatment decision and this can have positive effects on patients satisfaction, compliance and health outcomes, as shown by Renzi et al. [17].

In Ghent, we came up with the concept of an educational programme that could be added to our standard treatment approaches for chronic dermatoses. Offering more support and education in the format of group sessions will improve

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Table 1 An overview of the activities and their part in the whole programme

Overview of activities	Teacher	Number of sessions	Duration one session	Total duration
1. Specific information on skin disease conditions				
a. Information session about skin diseases	Dermatologist	1	60 min	1 h
b. Skin care	Pharmacist and dermatologic nurse	3	120 min	6 h
2. Stress-reduction techniques				
a. Physical training	Sports teacher	12	60 min	12 h
b. Yoga	Yoga teacher	9	60 min	9 h
c. Mindfulness-based stress reduction	Mindfulness teacher	8	150 min	20 h
3. Information sessions on life style and psycho-dermatology				
a. Diet	Dietician	2	60 min	2 h
b. Responsible physical training	Training expert	1	60 min	1 h
c. Sleep hygiene	Psychiatrist	1	90 min	1.5 h
d. Smoking cessation	Psychologist	1	60 min	1 h
e. Substance abuse	Psychiatrist	1	90 min	1.5 h
f. Psycho-dermatology	Psychiatrist	1	90 min	1.5 h
g. Practical philosophy	Philosopher	2	60 + 90 min	2.5 h
4. Feedback				
a. Individual	Dermatologist	1	15 min	15 min
b. In group	Dermatologist	1	1 h	1 h
Total				60 h 15 min

the comprehension of the skin condition, change the attitude towards the disease, improve the adherence to prescribed therapy and improve quality of life. The novelty of this programme is that it is open to all diagnosis and that it combines cognitive educational sessions, stress-reduction techniques and additional skin workshops. Our programme runs 2- or 3-h sessions twice a week for 12 weeks. It was set up in 2006 and runs twice a year. Our purpose was to investigate the effect on quality of life of this educational programme for patients with chronic skin diseases. Preliminary results of six runs of the programme are presented here.

Patients and methods

Patient population

Patients from any gender or race with a chronic skin disease such as psoriasis, atopic dermatitis or other types of eczema, chronic urticaria, acne, hidradenitis suppurativa, vitiligo... can enter the programme. Age range for inclusion is from 18 years onwards.

Content of the educational programme

The educational programme consists of 2-h sessions twice a week for 12 weeks. An interdisciplinary team of trainers is involved: dermatologist; dermatologic nurse; pharmacist;

psychiatrist; psychologist; dietician; philosopher; training expert; sports, mindfulness and yoga teacher. An overview of the activities, and their share in the whole programme, is given in Table 1. The programme activities can be divided into four groups.

Specific information on skin disease conditions

In the first 1-h session, a dermatologist gives basic medical information on all diagnosis present in the patient group. Topics such as the definition of the different diseases, basic pathogenetic mechanisms, clinical symptoms, prognosis, and treatment of a given skin disease are carefully explained.

Furthermore, three skin care sessions of 2 h are offered. A pharmacist together with a dermatologic nurse present information on structural, biological and social functions of skin; specific skin disease problems such as xerosis, itch and scaling are tackled.

Stress-reduction techniques

Physical training Patients get acquainted with a variety of group and individual sports during 12 weeks, 1 h per week. The aim is to enhance the motivation for physical training on a regular basis and let patients find what type of sports is best of fit for them. This training scheme is preceded by a physical fitness assessment as a method for screening health risk prior to exercise and sport [4, 24].

Yoga Yoga combines many stress-reducing techniques, including exercise and learning to control the breath, clear the mind and relax the body. This group training is given in nine sessions of 1 h each [22].

Mindfulness-based stress reduction This technique is a behavioural intervention based on insight meditation. It aims to be alert for itch, pain and other sensations or moods and it prevents to be carried away by negative thoughts and reaction patterns. This is educated in eight sessions of 2, 5 h each on a weekly basis [16].

Information sessions on life style factors and psycho-dermatology

(a) *Diet* Two information sessions on composing a balanced diet are given by a dietician. The lessons accentuate the importance of healthy and varied nutrition. Moreover, specific topics about nutrition and skin are highlighted, such as food allergy, psoriasis and the metabolic syndrome...

(b) *Responsible physical training* In one session the elements of building condition and responsible training are explained. This session is given by a training expert.

(c) *Sleep hygiene* A session about sleep hygiene highlights the importance of good sleep and discusses sleep disorders. The different treatment options to optimize sleep are discussed. This session is given by a psychiatrist specialized in sleeping disorders.

(d) *Smoking cessation* In this session more insight is given in the association between smoking and skin diseases. Moreover, smoking cessation counseling is offered to the participants who smoke.

(e) *Substance abuse* Substance abuse is sometimes the consequence of the burden of a chronic disease which again has a negative influence on the course of the disease. During this session, information is given about alcohol abuse, the short- and long-term effects and treatment. This session is given by a psychiatrist.

(f) *Psycho-dermatology* A session of psycho-dermatology informs about the common underlying psychopathological disorders that often accompany chronic dermatoses, and ways to counter them. This session is given by a psychiatrist.

(g) *Practical philosophy* Two philosophical sessions are included in the programme to inspire the patients on a paradigm shifting with regard to their disease. These lessons are given by a philosopher.

Of all cognitive interventions, including the skin information sessions, a syllabus is offered to the patients.

Feedback The dermatologist also sees the patients halfway the programme on an individual basis to answer more individual questions, and at the end, in a group evaluation session.

Evaluations

Patients complete the following validated, self-administered quality of life questionnaires before the start of the programme and immediately after the programme: Dermatology Life Quality Index (DLQI), Skindex-29, Psoriasis Disability Index (PDI) and Quality of Life Index for Atopic Dermatitis (QoLIAD). DLQI and Skindex-29 are dermatology-specific quality of life instruments. DLQI consists of ten questions concerning patients' perception of the impact of skin diseases on different aspects of their quality of life over the last week. The results of a few studies investigating the clinical meanings of the DLQI score show a minimal clinical important difference between 2.2 and 6.9 depending on the skin disease [5]. The Skindex-29 consists of 30 items divided in three scales, assessing burden of symptoms, social functioning and emotional state. The questions refer to the previous 4-week period, and scores are given on a 5-point scale, from 'never' to 'all the time' [1]. PDI and QoLIAD are disease-specific quality of life instruments for psoriasis and atopic dermatitis, respectively. The PDI is a 15-item scale that specifically addresses self-reported disability in areas of daily activities, employment, personal relationships, leisure and treatment effects [14]. QoLIAD consist of 25 questions and measures the impact of atopic dermatitis on quality of life in adults. In these four questionnaires a higher score indicates a greater negative impact of the skin disease on the quality of life [23].

The physical fitness assessment preceding participation to the programme measures body mass index (BMI), fat percentage and the physical condition of the patients based on VO_2 max. For the determination of the fat percentage, the Parizkova-method was used. In this method the skin fold thickness is measured at ten different locations on the body. For the determination of the VO_2 peak, the subjects perform an incremental ramp exercise test on a cycle ergometer (Lode Excalibur Sport, The Netherlands) with a rate of increase in work rate ranging between 10 and 25 $Watt\ min^{-1}$ depending on the anthropometrics and the fitness level of the individuals. The pulmonary gas exchange is registered breath-by-breath by means of the Jaeger Oxycon Pro (Germany) and the VO_2 max is determined as the highest VO_2 over a period of 30 s. The condition of the participants based on the VO_2 max is divided into five categories (weak, low, average, good and very good) according to gender and age.

Statistical analysis

Statistical analysis of the data were performed using PASW software version 18. The paired student *t* test was used to compare continued variables. Parametric tests

could be performed because the continued variables were distributed normally.

Results

Currently six runs of the programme have been completed. A total of 55 patients participated. Forty-three patients completed the programme, twelve dropped out, including eight men and four women (nine psoriasis, one atopic dermatitis, one prurigo and one acne). The reasons for drop-out were lack of time, depression, infection of locomotor disability.

Included diagnoses were psoriasis, atopic dermatitis, prurigo, alopecia areata, pemphigus, hidradenitis suppurativa, acne, chronic urticaria, morphea and seborrheic dermatitis. In Table 2 the number of patients is given that started and completed the programme, completed the physical fitness assessment and completed the quality of life questionnaires. Mean age of the total group ($n = 55$) was 45 years (range 25–69 years). The physical fitness test preceding participation to the programme revealed the following values for BMI, fat percentage and patient physical condition (based on VO_2 max): for women ($n = 28$), mean BMI was 26.3 kg/m^2 (SD ± 5.4), mean fat percentage was 26.5% (SD ± 6.6) and mean VO_2 max was 27.5 ml/min kg (SD ± 7.5). For men ($n = 25$), mean BMI was 25.9 kg/m^2 (SD ± 4.0), mean fat percentage was

19.4% (SD ± 6.0) and mean VO_2 max was 35.9 ml/min kg (SD ± 9.8). The mean condition in women is weak in 21%, low in 46%, average in 25% and good in 7%. In men the mean condition is weak in 12%, low in 24%, average in 32%, good in 28% and very good in 4%. The mean BMI of psoriasis patients was 27.5 ($n = 25$, SD ± 4.9) and mean BMI of atopic dermatitis patients was 23.8 ($n = 15$, SD ± 3.0).

Quality of life

For 39 patients a DLQI score and of 27 patients a Skindex-29 score was obtained before and after the programme. Overall, mean DLQI improved by 5.64 points ($p < 0.001$; SD ± 6.09) and mean Skindex-29 by 19.67 points ($p < 0.001$; SD ± 17.37).

Additionally, a PDI score was obtained from nine psoriasis patients and a QoLIAD score was obtained from 13 atopic dermatitis patients before and after the programme. In psoriasis patients, mean DLQI ($n = 15$) improved by 3.93 points ($p = 0.015$; SD ± 5.50), mean Skindex-29 ($n = 9$) improved by 23.33 points ($p = 0.020$; SD ± 24.15) and mean PDI ($n = 9$) improved by 7.44 points ($p = 0.019$; SD ± 7.60). In atopic dermatitis patients mean DLQI ($n = 15$) improved by 6.33 points ($p = 0.003$; SD ± 6.73), mean Skindex-29 ($n = 14$) improved by 17.50 points ($p < 0.001$; SD ± 9.97) and mean QoLIAD ($n = 13$) improved by 4.39 points ($p = 0.036$; SD ± 6.69).

Table 2 Number of patients that started and ended the programme, completed the physical fitness assessment, and completed the quality of life questionnaires before and after the programme: dermatology

Diagnosis	Number of patients						
	Started programme	Completed physical fitness assessment	Ended programme	Completed DLQI before and after	Completed Skindex-29 before and after	Completed PDI before and after	Completed QoLIAD before and after
Psoriasis	26	25	17	15	9	9	0
Atopic dermatitis	16	15	15	15	14	0	13
Prurigo	3	3	2	2	0	0	0
Alopecia areata	2	2	2	1	1	0	0
Pemphigus	2	2	2	1	1	0	0
Hidradenitis suppurativa	2	2	2	2	1	0	0
Acne	1	1	0	0	0	0	0
Chronic urticaria	1	1	1	1	0	0	0
Morphea	1	1	1	1	0	0	0
Seborrheic dermatitis	1	1	1	1	1	0	0
Total	55 (25 men/30 women)	53 (a)	43	39 (b)	27 (c)	9 (d)	13 (e)

(a) Two patients did not take part in the physical fitness assessment at the start of the programme; (b) Of 43 patients who completed the programme, 4 patients did not fill out DLQI questionnaire; (c) Only 27 of 43 patients filled out Skindex-29 because this questionnaire was only introduced since the second programme; (d) Only 9 of the 17 psoriasis patients who ended the programme filled out a PDI because this questionnaire was only introduced since the second programme; (e) Of 15 atopic dermatitis patients who completed the programme, two patients did not complete QoLIAD

Table 3 Mean values and standard deviation (\pm SD) of dermatology life quality index (DLQI) and Skindex-29 outcomes are given for each diagnosis

Diagnosis	Mean DLQI before (\pm SD)	Mean DLQI after (\pm SD)	Mean improvement in DLQI (\pm SD)	Mean Skindex-29 before (\pm SD)	Mean Skindex-29 after (\pm SD)	Mean improvement in Skindex-29 (\pm SD)
Psoriasis	9.87 (\pm 6.63)	5.93 (\pm 6.01)	3.93 (\pm 5.50; * $p = 0.015$)	54.78 (\pm 22.47)	31.44 (\pm 19.99)	23.33 (\pm 24.15; * $p = 0.020$)
Atopic dermatitis	14.80 (\pm 6.77)	8.47 (\pm 3.29)	6.33 (\pm 6.73; * $p = 0.003$)	70.36 (\pm 11.96)	52.86 (\pm 10.30)	17.50 (\pm 9.97; * $p < 0.001$)
Prurigo	9.50 (\pm 9.19)	3.00 (\pm 0.00)	6.50 (\pm 9.19; * $p = 0.500$)			
Alopecia areata	6.00	0.00		38.00	19.00	
Pemphigus	9.00	11.00		46.00	52.00	
Hidradenitis suppurativa	17.50 (\pm 3.54)	6.00 (\pm 0.00)	11.50 (\pm 3.54; * $p = 0.136$)	91.00	40.00	
Acne						
Chronic urticaria	18.00	10.00				
Morphea	14.00	0.00				
Seborrheic dermatitis	6.00	2.00		37.00	25.00	
Total	12.23 (\pm 6.75)	6.59 (\pm 4.82)	5.64 (\pm 6.09; * $p < 0.001$)	62.59 (\pm 19.25)	42.93 (\pm 17.68)	19.67 (\pm 17.37; * $p < 0.001$)

Mean improvement in DLQI and Skindex-29 is calculated by the difference in mean values before and after the programme

*significance value

Table 4 Mean values and standard deviation (\pm SD) of psoriasis disability index (PDI) and quality of life index for atopic dermatitis (QoLIAD) outcomes are shown

	Mean before (\pm SD)	Mean after (\pm SD)	Mean improvement (\pm SD)
Psoriasis: PDI	12.00 (\pm 6.78)	4.56 (\pm 5.25)	7.44 (\pm 7.60; * $p = 0.019$)
Atopic dermatitis: QOLIAD	13.15 (\pm 3.85)	8.77 (\pm 5.60)	4.39 (\pm 6.69; * $p = 0.036$)

Mean improvement in PDI and QOLIAD is calculated by the difference in mean values before and after the programme

*significance value

The mean values of the questionnaires before and after the programme for each diagnosis are given in Tables 3 and 4.

Discussion

In the present article, we have described the goals, content and preliminary results of a novel educational programme that we introduced as an additional therapy to the standard treatment for chronic skin diseases.

The results of the physical fitness test before the programme showed overweighted patients ($n = 53$, mean BMI = 26.1 kg/m²). Mean fat percentage in men (19.4%) and women (26.5%) was higher than in normal healthy population (17% in men and 23% in women). The mean condition in women was weaker than in men; however, 36% of male participants have also a weak or low condition. The results of the physical condition test therefore emphasize the importance of managing lifestyle factors such as diet and exercise.

Furthermore, validated questionnaires revealed that the health related quality of life significantly improved after the intervention. Specifically, women with atopic dermatitis ($n = 9$) seemed to benefit most from the programme with regard to quality of life.

An important goal of our educational programme is to improve patients adherence to therapy. Good evidence shows that office visits drive patients adherence behaviour. Even independent of the content of the visits, our twice a week visits could have an effect on patients compliance to treatment.

Several concepts of educational and behavioural interventions have been described for skin diseases, in particular for psoriasis [12, 15], atopic dermatitis [9, 18] and chronic pruritus [6, 10, 20]. These programmes have in common that they contain education on the skin disease, education on the lifestyle factors and stress-reducing techniques but they slightly differ in their approach depending on the skin disorder. They are conducted ranging from one to six sessions up to 6 weeks. The overall results of these studies show improved quality of life and clinical outcome compared with a control group.

The major difference with our concept is the intensity and the diversity of our programme: our programme runs 2-h sessions twice a week for 12 weeks including education about skin diseases, skin care work-shops, education about lifestyle and stress-reduction techniques such as yoga, physical training and mindfulness-based stress reduction. Limitations to our preliminary data are lack of a control group and lack of a clinical outcome measurement. Finally, we could not control for changes in other aspects

of the patients' managements, such as changes in the pharmacological therapy.

Conclusions and future perspectives

The objective of our programme was to support patients in the self-management of their skin disease in a holistic manner. Education about skin diseases and stress-reduction techniques were the basic elements of our programme. In addition, we wanted to accentuate the approach of lifestyle factors as diet, exercise, sleep, alcohol and smoking [19]. Lifestyle factors can influence the course of skin diseases especially in psoriasis in which an increased incidence of the metabolic syndrome and cardiovascular disease has recently drawn attention [13].

With the description of the elaboration of the programme and its preliminary outcome we want to be of help in defining and setting up future standardized preferably multi-center trials with a critical set-up for evaluation. Warsi et al. [21], Ersser et al. [9] and Chida et al. [8] emphasize the need for rigorously designed trials with well-validated interventional instruments, maximal reduction of possible bias, and better description of important variables such as patient educational level, disease duration and severity and social support.

This initiative for patients with chronic dermatoses was experienced as a valuable addition to classical treatment. Quality of life with regard to specific skin problems was improved. These positive initial results are stimulating to set up a prospective controlled randomised trial investigating the impact on the quality of life, the clinical efficacy and the cost-effectiveness (in light of restricted health care budgets) of this educational intervention programme, in a group of patients with chronic skin diseases. In view of all this, we call for a multi-center European study in this field.

Acknowledgments Supported by unrestricted grants of Pierre Fabre SA, Schering-Plough, Wyeth, LEO Pharma, Special thanks to the teachers: Strubbe Frederik, De Potter Marie-Amélie, Moreau Els, Lemmens Gilbert, Mariman An, Algoet Peter, Bourgois Jan, Boudrez Hedwig, De Bisschop Kristel, Geirnaert Mia, Soetaert Ann and Lutgarde Jenkins for practical follow up.

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